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ABSTRACT

This report is the fifth in a series detailing the impact of the injection-related AIDS epidemic on African Americans and Latinos. Ten chapters include: (1) "Health Emergency: The Spread of AIDS among African Americans Who Inject Drugs"; (2) "Health Emergency: The Spread of AIDS Among Latinos Who Inject Drugs"; (3) "A Neglected Opportunity: Drug Treatment as AIDS Prevention"; (4) "The Scientific Evidence: Needle Exchange Programs Prevent HIV and Can Reduce Drug Use"; (5) "The Legality of Saving Lives"; (6) "Saving Lives and Saving Billions of Health Care Dollars"; (7) "Health Emergency: African American and Latina Women and Their Children"; (8) "Hepatitis C: Sometimes Deadly Disease Where Sterile Needles Can Save Lives and Dollars"; (9) "Medical Treatment for AIDS is AIDS Prevention: African Americans and Latinos are Disadvantaged"; and (10) "What Must Be Done." The report indicates that over 165,000 African Americans and 76,000 Latinos were living with injection-related AIDS or had died from it by the end of 2001. Many thousands more were infected with HIV. The HIV/AIDS epidemic has affected African Americans and Latinos much more significantly than whites who inject drugs. Recommendations include permitting possession of sterile needles and permitting and funding needle exchange programs. (SM)

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HEALTH EMERGENCY 2003

The Spread of Drug-Related AIDS and Hepatitis C Among African Americans and Latinos

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Dawn Day, PhD

with a Foreword by Joycelyn Elders, MD
Former US Surgeon General

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HEALTH EMERGENCY *2003*

The Spread of Drug-Related AIDS and Hepatitis C Among African Americans and Latinos

Dawn Day, PhD

with a Foreword by Joycelyn Elders, MD
Former US Surgeon General

Executive Summary

Health Emergency Among African Americans

- More than 165,000 African Americans were living with injection-related AIDS or had already died from it by the end of 2001. Many thousands more were infected with the HIV virus.

- The HIV/AIDS epidemic has fallen much more harshly upon African Americans than on whites who inject drugs. Among those who inject drugs, African Americans are five times as likely as whites to get AIDS.

- In 2000, with all the advances in AIDS treatment, AIDS was still among the top three leading causes of death for African Americans aged 25-54 years. More than half of those deaths were caused by contaminated needles.

Health Emergency Among Latinos

- More than 76,000 Latinos living in the United States and Puerto Rico had injection-related AIDS or had already died from it by the end of 2001. Thousands more were infected with the HIV virus.

- The HIV/AIDS epidemic has fallen more harshly upon Latinos than on whites who inject drugs. Among those who inject drugs, Latinos are at least one and a half times as likely as whites to get AIDS.

- In 2000, with all the advances in AIDS treatment, AIDS was still among the top five leading causes of death for Latinos aged 25-54. More than half of those deaths were caused by contaminated needles.

What Must Be Done

We must improve drug education. We must expand drug treatment programs. We must implement the proven public health interventions that can reduce substantially the spread of AIDS and hepatitis C among people who inject drugs by reforming our laws and regulations to:

- Permit possession of sterile needles

- Permit pharmacies to sell syringes without prescriptions

- Permit and fund needle exchange programs

Foreword

This powerful report brings home the severity of the problem of AIDS spread through dirty needles.

It makes me angry!

Dr. Elders

We have got to be about preventing disease! We have better drugs, but we still don't have a vaccine or a cure for this disease. We have watched people die from this disease; now they must learn how to live with HIV/AIDS. But why can't we help prevent this disease by providing clean needles? We do not allow people to get the clean needles that would reduce the spread of HIV disease, yet we spend thousands of dollars to treat each person who develops AIDS, to take care of them, to watch them die. That makes no sense! We have got to be about preventing problems, not fixing things after they are broken.

Our best scientific research shows that needle exchange programs do not increase drug use, but do reduce the spread of HIV. We need to speak out. Silence about the importance of needle access programs is causing the deaths of thousands of our bright young black and Latino men and women. Time is slipping away. Our bright young people are slipping away.

We must recognize the spread of AIDS through dirty needles as the public health problem that it is. We must accept the scientific data and stand up for needle access programs and begin to save precious lives!

Dr. Joycelyn Elders
Former U.S. Surgeon General

About the Author

This report was prepared by Dawn Day, Director of the Dogwood Center, an independent research organization in Princeton, New Jersey. Dr. Day is an activist scholar with 30 years of experience as a researcher and writer on social issues.

This report is the fifth in a series detailing the impact of the injection-related AIDS epidemic on African Americans and Latinos. Dr. Day has devoted much of the last few years to educating the public on the importance of needle access for HIV and hepatitis C prevention in a variety of forums, including lectures, newspaper articles and television and radio appearances.

In the course of her work on HIV and hepatitis C prevention, Dr. Day has received grants from several funders including the Robert Wood Johnson Foundation, the Angelica Foundation, Common Sense for Drug Policy, Robert E. Field, the Criminal Justice Policy Foundation, the Partnership for Responsible Drug Information, and the Drug Policy Alliance. She has reviewed grant proposals for the Centers for Disease Control and Prevention.

Among Dr. Day's publications dealing with racial discrimination are *Adoption Agencies and the Adoption of Black Children* (Lexington Books, 1979) and *Protest, Politics and Prosperity: Black Americans in White Institutions, 1940-1975* (Pantheon, 1978; co-author).

Holding both a PhD in sociology and an MSW in social work from the University of Michigan, she has taught at Brooklyn College and the University of Maryland.

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For Copies

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1. Health Emergency: The Spread of AIDS Among African Americans Who Inject Drugs

More than 165,000 African Americans were living with injection-related AIDS or had already died from it by the end of 2001. Many thousands more were infected with the HIV virus.[1] About a third of those with HIV/ADS are unaware that they are infected.[2]

More than 165,000 African Americans were living with injection-related AIDS or had already died from it by the end of 2001.

The HIV/AIDS epidemic has fallen much more harshly upon African Americans than on whites who inject drugs. *Among those who inject drugs*, African Americans are five times as likely as whites to get AIDS.[3]

In the five years ending in 1999, the number of African Americans living with drug-related AIDS more than doubled.[4]

AIDS deaths are down because of the new medicines that have been developed. In 2000, however, AIDS was still among the top three leading causes of death for African Americans aged 25-54 years.[5] More than half of AIDS deaths among African Americans are caused by contaminated needles.[6]

A person can stop injecting drugs, and many do. Once infected, though, there is no cure for HIV. With AIDS deaths down and the number of people living with injection-related AIDS increasing, prevention is becoming more and more important.

The HIV/AIDS epidemic has fallen much more harshly upon African Americans than on whites who inject drugs. Among those who inject drugs, African Americans are five times as likely as whites to get AIDS.

For injecting drug users, prevention must include making sterile needles more accessible. A survey done in 2000 reveals that the majority of African Americans favor improving needle access to prevent HIV among people who inject drugs. The majority support needle exchange programs,

pharmacy sale of sterile syringes without a prescription, and physician prescription of syringes for HIV prevention.[7]

The HIV/AIDS epidemic among African Americans infected through use of dirty needles does not stop with them. The HIV/AIDS epidemic spreads outward to non-drug-injecting wives, husbands and lovers and then to newborn babies.

The role of racial profiling and needle possession laws in the spread of AIDS

Permitting access to sterile needles could substantially reduce the spread of HIV among people who inject drugs. No research has ever shown that making needle possession illegal is effective in reducing drug use in the United States. Our needle-possession laws have been effective, however, in making sterile needles scarce and in creating the circumstances in which people who inject drugs share their infected needles, resulting in the further spread of HIV and other blood-borne diseases. In this way, an ineffective policy of drug control – denying access to sterile needles – has become a major factor in the spread of deadly disease.[8]

People can avoid arrest for possession of an illicit drug by buying the drug immediately before they plan to use it. In the numerous states where needle possession is illegal, those who carry their own clean needles are vulnerable to arrest at any time.

African Americans are more at risk in this regard because they frequently have been the target of police drives to enforce drug laws.[9] This shows up in the federal government's own data; blacks are only14 percent of all drug users but 35 percent of all those arrested on drug charges.[10] Official arrest records understate the situation. In many states and cities, pol. .e do not record the stops they make, if the stops do not result in arrests.[11]

We can now begin to see why the number of injection-related new AIDS cases is so high among blacks: being stopped and searched is much more common among blacks than among whites. This means that the legal system, via the police, is more likely to confiscate the personal needles of blacks. Also, because black users know (correctly) that they are vulnerable to arrest, these users are likely to "choose" not to carry their own clean needles. Users who do not carry their own needles all too often end up sharing the needles and blood-borne diseases of others.

Spreading HIV among African Americans who inject drugs is not the deliberate policy of any state government or police department. Nevertheless, by restricting access to sterile needles, and by targeting blacks for arrest, that has been the result.[12]

Spreading HIV among African Americans who inject drugs is not the deliberate policy of any state government or police department. Nevertheless, by restricting the access to sterile needles and by targeting blacks for arrest, that has been the result.

The infamous Tuskegee syphilis "experiment"

In our society, medical intervention goes far beyond the use of pills, bandages, and surgery; in the name of public health we remove asbestos and lead-based paint and treat water. Given the med-

ical consensus that has emerged on the effectiveness of sterile needles as a way to avoid the spread of injection-related AIDS, it is difficult to see the denial of access to sterile needles as anything other than the denial of access to a lifesaving medical intervention.

In the history of modern medicine in the United States, there is only one other instance where a lifesaving medical intervention involving the spread of a deadly, infectious disease was deliberately denied a group of people. That instance is the infamous Tuskegee syphilis "experiment." The originators justified themselves by saying they wanted to study the course of untreated syphilis. The unfortunate victims of this study were 400 black men from Alabama, who were denied medical treatment for their syphilis from 1932, when the study began, until their deaths or, if they lived, until 1972, when the "experiment" was exposed and stopped.[13]

The absence of genetic protection

Scientists have discovered that certain genes offer protection against the initial infection with HIV or slow the speed with which HIV/AIDS progresses. This genetic protection has been found in between 4 and 17 percent of whites and 2 percent of Puerto Ricans. So far, such genetic protection has been found to be almost nonexistent in Africans, Asians, and Pacific Islanders.[14]

It is difficult to see the denial of access to sterile needles as anything other than the denial of access to a lifesaving medical intervention.

2. Health Emergency: The Spread of AIDS Among Latinos Who Inject Drugs

More than 76,000 Latinos living in the United States and Puerto Rico had injection-related AIDS or had already died from it by the end of 2001. Thousands more were infected with the HIV virus.[1] About a third of those with HIV/ADS are unaware that they are infected.[2]

The HIV/AIDS epidemic has fallen more harshly upon Latinos than on whites who inject drugs. *Among those who inject drugs*, Latinos are one and a half times as likely as whites to get AIDS. The true figure could be substantially higher.[3]

More than 76,000 Latinos living in the United States and Puerto Rico had injection-related AIDS or had already died from it by the end of 2001.

In the five years ending in 1999, the number of Latinos living with drug-related AIDS more than doubled.[4]

AIDS deaths are down because of the new medicines that have been developed. But in 2000, AIDS was still among the top five leading causes of death for Latinos aged 25-54.[5] More than half of AIDS deaths among Latinos are caused by contaminated needles.[6]

A person can stop injecting drugs, and many do. Once infected, though, there is no cure for HIV. With AIDS deaths down and the number of people living with injection-related AIDS increasing, prevention is becoming more and more important.

For injecting drug users, prevention must include making sterile needles more accessible. A survey done in 2000 revealed that over 60 percent of Latinos favor improving needle access to prevent HIV among people who inject drugs. Over 60 percent support needle exchange programs, pharmacy sale of sterile syringes without prescriptions, and physician prescription of syringes for HIV prevention.[7]

The AIDS epidemic among Latinos infected through contaminated needles does not stop with them. The AIDS epidemic spreads outward to

The HIV/AIDS epidemic has fallen more harshly upon Latinos than on whites who inject drugs. Among those who inject drugs, Latinos are one and a half times as likely as whites to get AIDS.

non-drug-injecting wives, husbands and lovers and then to newborn babies.

Ethnic profiling

Concern about racial profiling by Latino organizations and Latino police officers makes it evident that ethnic profiling by law enforcement is also having a serious negative impact on Latinos.[8] The aggressive enforcement of needle possession laws against Latino men and women is causing needle sharing and the spread of HIV/AIDS among Latinos in the same way that it is among African Americans.

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Impact of undocumented immigration

Fearing deportation, undocumented Latino immigrants live a secretive existence. This affects their health and the spread of HIV. In the worst cases immigrants are dying because they cannot access health care, or they are spreading disease because they do not know they are infected.[9]

Undocumented HIV-infected immigrants without medical insurance get a patchwork of inconsistent care, turning to emergency rooms for treatment of opportunistic infections and then returning to the shadows. They cannot become citizens. U.S. immigrant status is not granted to those with HIV or those sick with other conditions who may need public health or welfare benefits.[10]

In this picture of neglect, tragedies abound – for the infected individuals and for those who will become infected through needle sharing and risky sex. HIV/AIDS knows no boundaries; those newly infected will include U.S. residents, as well as other undocumented immigrants.

The absence of genetic protection

Scientists have discovered that certain genes offer protection against the initial infection with HIV or slow the speed with which HIV/AIDS progresses. This genetic protection has been found in 4 to 17 percent of whites and 2 percent of Puerto Ricans. The gene has generally not been detected in indigenous non-European populations; so, to the limited extent that such protective genes exist in Latino populations originating in Central or South America, the protection is probably the result of European gene flow.[11]

In the worst cases undocumented Latino immigrants with HIV are dying because they cannot access health care, or they are spreading disease because they do not know they are infected.

3. A Neglected Opportunity: Drug Treatment as AIDS Prevention

Drug treatment is also HIV prevention. People in treatment are less likely to inject drugs. People in treatment are less likely to get involved in risky sex, another way to contract HIV. Yet only a minority of those who need drug treatment are currently receiving it.

Methadone maintenance is the most effective treatment for heroin, the most commonly injected drug. Yet of the estimated 600,000 to 1,000,000 heroin users in the U.S., methadone maintenance is available to less than 200,000.[1]

The federal government spends between 10 and 15 percent of the nation's drug-control budget to treat drug-dependent individuals.[2] Experts, both inside and outside government, agree that it would be both cost effective and humane to increase the government's expenditures on drug treatment.[3] Nonetheless we limit our expenditures on drug treatment, while providing almost unlimited funds for imprisoning nonviolent drug users. Methadone maintenance treatment for heroin addiction costs about $4,700 per person per year; prison about $18,700 per person per year.[4]

Experts, both inside and outside government, agree that it would be both cost effective and humane to increase the government's expenditures on drug treatment. Nonetheless we limit our expenditures on drug treatment, while providing almost unlimited funds for imprisoning nonviolent drug users.

Expanding drug treatment is not enough. Drug dependence is a chronic, relapsing disease. This means that some in treatment will, in fact, relapse.[1] Others, although we may think they need treatment, are not yet interested in it. All these considerations lead to the significant conclusion that expanding drug treatment alone cannot stop the spread of HIV among people who inject drugs; access to sterile needles is needed as well.

Expanding drug treatment alone cannot stop the spread of HIV among people who inject drugs; access to sterile needles is needed as well.

4. The Scientific Evidence: Needle Exchange Programs Prevent HIV and Reduce Drug Use

The Scientific Evidence: Sterile Needles Are Needed For HIV Prevention

Access to sterile needles is essential for HIV prevention among injecting drug users. According to the Centers for Disease Control and Prevention:

> **For injection drug users who cannot or will not stop injecting drugs, using sterile needles and syringes only once remains the safest, most effective approach for limiting HIV transmission.**[1]

Uninfected men and women who inject drugs need sterile needles so they can avoid becoming infected. People already infected with HIV/AIDS who inject drugs need sterile needles so they will not, when asked for a needle, pass a used one on to someone else, spreading the HIV virus further.

One effective way to get sterile needles to injecting drug users is to set up needle exchange programs that distribute sterile needles and collect used ones.[2] Where it is legally possible, pharmacy sale of syringes without a prescription is also an effective way to get sterile syringes to injectors. A study of 96 US metropolitan areas found that the rate of HIV among drug users was twice as high in the metro areas that prohibited direct sale of syringes than in those that did not.[3]

The Scientific Evidence: Needle Access Programs DO NOT INCREASE Drug Use

Those opposed to needle exchange programs have expressed the concern that needle exchange programs might increase drug use.

However, extensive scientific research has been done on the relationship between access to sterile needles and drug use. Eight major, government-funded studies have concluded that needle exchange programs *do not increase* drug use among current users and that needle exchange programs *do not attract* new people to drug use.[4]

Convinced by the strong evidence that access to clean needles is essential to controlling the HIV epidemic among injecting drug users, three former U.S. Surgeons General (David Satcher, MD, Joycelyn Elders, MD and C. Everett Koop, MD), the American Medical Association, the American Pharmaceutical Association, and other professional health associations have called on their members to support the establishment of needle exchange programs and to work to reform the state laws and pharmaceutical board regulations that limit access to sterile needles from pharmacies.[5]

In the face of the overwhelming scientific evidence in favor of needle exchange programs, the ban on federal funding of needle exchange programs continues. Since access to sterile needles is the primary way of preventing HIV among those unwilling or unable to stop injecting drugs, this means that none of the almost billion in prevention dollars[6] spent each year can be spent to prevent HIV among the group that accounts for 35 percent of the HIV/AIDS epidemic.[7]

Careful studies have shown that needle exchange programs can reduce drug use.

The Scientific Evidence: Needle Exchange Programs CAN REDUCE Drug Use

After carefully examining the relevant research, the National Institute on Drug Abuse has concluded that needle exchange programs can actually reduce drug use.[8] Needle exchange programs work on two levels to reduce drug use: the interpersonal and the institutional.

The interpersonal level. Needle exchange workers often offer information counseling and a friendly ear to drug users who, in many cases, have little contact with individuals outside the drug-using world. This interaction, often focused on helping the drug user take better care of himself, can empower the drug user to decide for himself or herself to cut back on drug use or enter treatment.

The institutional level. Needle exchange programs have helped drug treatment agencies become more receptive to poor and minority clients. Some needle exchange programs have negotiated agreements with drug treatment agencies, so that the exchange is guaranteed a certain number of openings in the treatment organization. Other exchanges have arranged for free treatment for some injecting drug users who lack resources.

The New Haven needle exchange experience illustrates this process. While the main focus of the New Haven program was on exchanging needles, considerable effort also went into creating drug treatment opportunities for those who wished to take advantage of them. One-sixth of the injecting drug users who initially got syringes from the needle exchange subsequently entered drug treatment programs.

Referrals from the New Haven needle exchange also helped redress racial/ethnic inequities in the drug treatment system. Prior to the start of needle exchange program referrals, less than 40 percent of the injecting drug users in the area treatment programs were minorities, while over 60 percent of those placed in drug treatment by the needle exchange were minorities.[9]

Careful studies in Maryland, Hawaii, and Washington state have all shown that needle exchange programs, given community support and the appropriate resources, can reduce drug use.[10]

Development of the interpersonal and institutional relationships that lead to reduced drug use occurs most effectively when the exchange has a secure legal status. When a needle exchange is under pressure from the police, conversations between clients and volunteers are cut short, and the program's resources to encourage change in the drug treatment agencies are limited or nonexistent.[11]

Thus, ironically, those who use police power to harass or close down needle exchange programs are not only causing the spread of HIV but are also causing a continuation of drug use by hampering the needle exchange activities that would otherwise help some drug users reduce their drug use or quit entirely.

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5. The Legality of Saving Lives

According to the Centers for Disease Control and Prevention: **For injection drug users who cannot or will not stop injecting drugs, using sterile needles and syringes only once remains the safest, most effective approach for limiting HIV transmission.**[1]

The numerous state and local laws and regulations that limit access to sterile needles were put in place just as the not-yet-understood HIV/AIDS epidemic was beginning to spread across the United States. With no scientific studies to support their thinking, lawmakers merely assumed that if access to syringes were limited, injecting drug use would be reduced.[2]

This assumption proved tragically wrong. Limiting access to sterile needles did reduce the supply of sterile needles, but it did not reduce injecting drug use. Injecting drug use continued apace as users shared needles – and, consequently, their HIV and hepatitis C infections – as well.

The all-too-slow process of reform

Elimination of the barriers to accessing sterile needles is coming all too slowly. The **first wave** of reform in any city or state often occurs as a few activists, concerned with saving lives *right now*, set up a needle exchange, giving out sterile needles and collecting used ones.[3] This direct action cuts through restrictive laws and regulations; but it is risky and requires courage. The activists see themselves as public health workers; some police, prosecutors, elected officials, and community members see them as criminals.

The first wave of reform in any city or state often occurs as a few activists, concerned with saving lives right now, set up a needle exchange, giving out sterile needles and collecting used ones.

In **the second wave** of reform, activists gain local support, and the local legal situation is reconfigured to give the needle exchange staff and participants protection from arrest for needle possession. In the most successful instances of reform, such as in the states of Connecticut, Hawaii, and New Mexico, the state government, through its health department, begins running needle exchanges and expands service to other areas of the state where it is needed.[4]

The third wave of reform involves changing laws and regulations so that pharmacists can sell syringes without a prescription. To be effective, the pharmacy effort has to include educational programs to inform pharmacists of the public health importance of over-the-counter sales of syringes.[5] Care also must be taken that syringes are sold without regard to race or ethnicity. A St. Louis study, for example, found that several pharmacies were willing to sell syringes to whites but not to African Americans.[6]

As of June 2002, California, Delaware, Illinois,

Massachusetts, New Jersey, and Pennsylvania are the only remaining states with severely restrictive syringe prescription laws or regulations.

A promising **fourth wave** of reform, one just beginning, is physician prescription of syringes. Prescribing syringes to prevent the spread of HIV is a legitimate medical purpose. The relevant governing bodies in Rhode Island have recognized this to be the case, and some injecting drug users in that state are now able to get syringes by prescription from their doctor.[7]

In an analysis of the 50 states, District of Columbia, and Puerto Rico, legal experts found that physician prescription of injection equipment to patients as a means of preventing disease transmission during drug use was clearly legal in 48 of the 52 jurisdictions and filling the prescriptions in pharmacies was clearly legal in 26.[8] In the jurisdictions where physician prescription and pharmacy filling of those prescriptions is legal, it is a question of helping doctors, pharmacies, and medical societies become aware of the situation and act accordingly.

A **final wave** of reform involves changing the laws governing drug paraphernalia. As of June 2002, 12 states excluded syringe possession from their drug paraphernalia laws (Alaska, Connecticut, Hawaii, Maine, Minnesota, New Hampshire, New Mexico, New York, Oregon, Rhode Island, Washington, and Wisconsin).[9]

Laws prohibiting possession of sterile needles and other, related safe injection equipment (such as cookers and cotton) need to be removed from all state and local drug paraphernalia laws. Anything less will continue the spread of HIV and other blood-borne diseases.

Needle exchange programs today

In 2000, there were 154 needle exchange programs in the United States, up from 143 the previous year.[10] The exchanges were located in 106 cities and 35 states. Many major cities – including Baltimore, Chicago, Detroit, Honolulu, New York City, Philadelphia, and San Francisco – had needle exchange programs.

In 2000, there were 154 needle exchange programs in the United States, up from 143 the previous year.

In addition to exchanging syringes, many needle exchange programs provide a range of related services, including condom distribution to prevent sexual transmission of HIV and other sexually transmitted diseases; referrals to substance abuse treatment and other medical and social services; distribution of alcohol swabs to help prevent abscesses and other bacterial infections; on-site HIV testing and counseling; screening for tuberculosis, hepatitis B, hepatitis C, and other infections; and primary medical services.[11]

Receipt of state and local government funds is key to the expansion of services offered through needle exchange programs. In 2000, 62 exchanges reported funding from state or local governments.[12]

Progress in making needle exchange programs legal has been slow. Of the 121 exchanges responding to the question about their legal status, 83 were legal; 26 were illegal, and 12 were uncertain about their legal status.[13]

Needle exchanges as harm-reduction organizations

Needle exchange programs see themselves as part of a larger harm reduction movement. By slowing the spread of HIV, they are reducing the harm from injecting drug use. Without calling it that, we, as a society, practice harm reduction all the time. We reduce the harm of riding a motorcycle by requiring riders to wear helmets. We reduce the harm from car accidents by requiring people to wear seat belts. We reduce the harm to nonsmokers by requiring that smoking be done only in designated areas. We reduce the harm from excessive drinking at parties and bars by encourag-

ing the use of a designated driver who does not drink. By preventing the spread of HIV and other blood-borne diseases, needle exchange programs reduce the harm that comes from injecting drug use.

Making police into partners

In 2000, 37 needle exchange programs reported police interference of some sort. A common form of harassment occurs when officers confiscate syringes or force exchange participants to break the points off their syringes, thus increasing the likelihood of syringe sharing and HIV and hepititis C infection.[14]

Arrest or the threat of arrest can discourage donations, deter volunteers (thus effectively reducing the number of hours the exchange is open), and frighten away prospective clients. The threat of arrest can also force a program to move to a less accessible location, making it difficult for those who need the exchange's services to find it.[15] Any action that reduces the effectiveness of a needle exchange program limits the ability of the exchange to prevent HIV and get interested users into drug treatment.[16] In the worst case, arrest and prosecution can shut down a needle exchange entirely.[17]

Although some police officers remain confused about the role of needle exchange programs in disease prevention, when it is explained to them, many officers see both their own personal advantage and the public health benefits of needle exchange programs.

An officer patting down a suspect is much less likely to get a dangerous needle stick when the suspect is carrying a new syringe with its protective cap (which is legal and which the suspect feels free to mention) than when a suspect is hiding a used and, perhaps infected, illegal needle whose protective cap has long since been lost.[18]

The continuing epidemic

For those concerned about the spread of HIV/AIDS among injecting drug users, their non-drug-using sexual partners, and newborn children, the pace of needle access reform has been far too slow. Of the ten states with the highest rates of injection-related AIDS in 1998, substantial progress in reform has been made in three (Connecticut, New York, and Rhode Island). Some progress had been made in another three (Maryland, Massachusetts, and Pennsylvania), but virtually no progress had been made in four (Delaware, Louisiana, New Jersey, and Florida).[19]

Although some police officers remain confused about the role of needle exchange programs in disease prevention, when it is explained to them, many officers see both their own personal advantage and the public health benefits of needle exchange programs.

With 14,000 people in the United States being infected with HIV every year as a result of intravenous drug use, it is clear we must do more.[20] We need to continue to educate people to the harms of drug use, particularly injection drug use. And we must listen to the expertise and wisdom of our public health officials and make sterile needles legally available to people who inject drugs:

- We must eliminate the drug paraphernalia and drug prescription laws and regulations so that there will be no ambiguity about the legality of needle exchange programs and so that drug users can purchase and carry their

own clean, safe needles without fear of arrest.

- We must recognize that HIV prevention is a legitimate medical purpose, and encourage physicians to write syringe prescriptions for people who inject drugs.

As a humane society, we must reach the point where injecting drug users in every state can legally protect themselves from HIV and other blood-borne diseases and where needle exchange workers in every state are treated not as criminals but as the public health workers they are.

As a humane society, we must reach the point where injecting drug users in every state can legally protect themselves from HIV and other blood-borne diseases and where needle exchange workers in every state are treated not as criminals but as the public health workers they are.

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6. Saving Lives and Saving Billions of Health Care Dollars

The main purpose of HIV prevention among injecting drug users is to prevent human suffering and save lives. As it turns out, HIV prevention through needle access can also save billions of health-care dollars.

The sale of syringes through pharmacies costs taxpayers nothing. Syringe exchange programs are cost-effective. In 2000, the mean annual budget of syringe exchange programs was about $100,000.[1] The lifetime cost of treating one person with AIDS was estimated to be between $154,000 and $190,000.[2] In other words, the average syringe exchange program more than pays for itself by preventing the transmission of HIV to just two people each year.

Without the expansion of needle exchange programs, in the next five years, an estimated 80,000 people who inject drugs and their sexual partners and newborn children will become infected with HIV. If just a *quarter* of those infections could be prevented, the savings in medical costs would be over $3 billion.[3]

Right now, a number of needle exchange programs are struggling to survive. In many areas where they are needed, no needle exchanges exist at all, because there is no financial support. Federal funding of needle exchange programs is needed to bring about the expansion of these programs that can save many thousands of lives.[4] The failure to permit federal funding of needle exchange programs has brought criticism not only from public health leaders, but also political leaders, including Representative Donna Christian-Christensen, MD, chair of the Congressional Black Caucus' Health Brain Trust and Representative Xavier Becerra of the Congressional Hispanic Caucus. The NAACP has taken a stand in favor of needle exchange.[5]

So, here is the situation. Our best science shows that a combination of needle exchange programs and pharmacy sales of syringes could save thousands of lives and billions of health-care dollars, but these scientific findings have not yet influenced policy.[6] As a result, the federal government is spending billions to provide medical treatment for people with injection-related AIDS while providing no funding for sterile needle access programs that would prevent new infections among injecting drug users and their wives, husbands, or sexual partners and newborn children.

The federal government is spending billions to provide medical treatment for people with injection-related AIDS while not providing any funding for sterile needle access programs that would prevent new infections.

7. Health Emergency: African American and Latina Women And Their Children

At the end of 2000, 86,000 women were living with injection-related AIDS or had already died from it. Many thousands more were infected with HIV. African American and Latina women are the hardest hit; they accounted for over 75 percent of all women with injection-related AIDS in 2001.[1]

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In spite of the medical advances in AIDS treatment, AIDS was still a leading cause of death for African American and Latina women age 25 to 54 in 2000. AIDS was among the top *five* leading causes of death for African American women and was among the top *seven* leading causes of death for Latinas.[2] Over 60 percent of those AIDS deaths were injection-related.[3]

Infants with HIV

In the United States, mother-to-child HIV transmission has been drastically reduced – from a high of 2,500 perinatal HIV infections in 1992, to an estimated 300 to 400 annual infections in recent years.[4] The reductions have occurred because many HIV positive mothers now receive zidovudine therapy or other appropriate medical treatment, before and during birth, and because HIV-positive mothers have stopped breastfeeding their infants.[5]

The use of appropriate therapy has reduced the risk of HIV transmission from 25 percent for untreated mothers to 2 percent for those taking combinations of AIDS drugs. Our medical scientists have not yet figured out how to get that 2 percent down to zero. So, even with the best antiretroviral treatment, an estimated 130 infants will be born infected with HIV each year. The simple fact is, the best way to prevent infections in babies is to prevent infections in women.[6] Prevention of HIV among women also has the great benefit of saving women's lives and leaving healthy infants with their own healthy mothers.

The burden of HIV/AIDS falls most heavily on infants of color and their mothers. Some 80 percent of the infants born with HIV are African American or Latino.[7]

AIDS orphans

As women become infected and die of AIDS, they leave children behind. In 1998, there were 67,000 American children under the age of 18, mostly children of color, who had lost their mothers to the AIDS epidemic. More than half of these children were 12 or younger.[8]

Most of these orphans were not infected with HIV. Some were born before their mothers

In 1998, there were 67,000 American children, mostly children of color, who had lost their mothers to the AIDS epidemic.

became HIV-positive. Others were born free of HIV, even though they were born after their mothers became infected.

About one-fifth of the mothers of the now-orphaned children never injected drugs themselves; they were unfortunate in their relationships, becoming infected through heterosexual sex with a man who at one time injected drugs.[9]

About 45 percent of the mothers of these now-orphaned children became HIV positive because the mothers themselves injected drugs. We should not assume that, had these mothers lived, they would not have been good parents. Women who inject drugs at one point in their lives are not necessarily drug users for life. Some experiment for only a short time; others use drugs for longer periods and then stop successfully.

Children need their parents. As a society, we need to be following policies which ensure that as few children as possible are orphaned by AIDS.

Prevention through safe sex and sterile needles

In the United States, HIV acquired through injecting drug use is an important source of the HIV that is spreading to heterosexuals. Needle access programs that prevent HIV among injecting drug users are also a significant way to prevent HIV among their heterosexual partners.

Needle access programs are effective. Persuading men and women who inject drugs to use sterile needles has proven to be relatively easy. Persuading men to use condoms during sex is not so easy.[10]

To protect women and men from HIV, we need to do everything we can to keep the number of HIV-positive people as small as possible. We need to advocate for safe sex. But we also need sterile needle programs to save the lives of non-drug-injecting women and men, as much as we need sterile needle programs to save the lives of persons who inject drugs themselves.

The inescapable conclusion

With thousands of motherless children and about 60 percent of all AIDS cases among women caused directly or indirectly by HIV-infected needles, the case for clean-needle programs to save the lives of women and children and prevent the destruction of families could not be stronger.

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8. Hepatitis C – A Sometimes Deadly Disease Where Sterile Needles Can Save Lives and Dollars

Hepatitis C is a blood-borne virus that spreads rapidly when people share needles and other injection equipment. Fifty to 80 percent of users become positive within 6 to 12 months of beginning injection drug use.[1] Half of new hepatitis C cases are associated with injection drug use.[2]

Chronic hepatitis C infection can cause cirrhosis, end-stage liver disease, and liver cancer. With no vaccine available to prevent its spread, hepatitis C prevention among people who inject drugs, like HIV prevention, involves opening up drug treatment opportunities and improving access to sterile needles, cookers, and other injection equipment.

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Hepatitis C can pass from an infected woman to her newborn baby, although breastfeeding does not appear to transmit the virus.[3]

Of those initially infected with hepatitis C, about 85 percent end up with chronic hepatitis. After a period of 10 to 30 years with no symptoms, people with persistent hepatitis C infection experience a wide spectrum of symptoms ranging from none to end-stage liver disease.[4]

Standard care for someone with advanced cirrhosis of the liver or liver cancer costs $20,000 a year. The treatment of last resort for hepatitis C is a liver transplant, with each transplant costing an average of $300,000.[5]

The risk of sexual transmission of hepatitis C, though much lower than the risk associated with contaminated needles, is still present. The highest rates of sexual transmission of hepatitis C are associated with multiple sex partners and with traumatic sex that results in blood exposure.[6]

As with AIDS, hepatitis C is a deadly epidemic of a blood-borne disease where exposure through blood transfusion has been almost eliminated, where infected mothers may pass on their disease to their newborn children, and where a major factor in the spread of the disease is shared injection equipment.

The first steps in the prevention of hepatitis C among people who inject drugs – establishing needle exchange programs and permitting pharmacy sale of syringes without a prescription – are very inexpensive. Without prevention, there can be pain, suffering, death – and expensive medical bills.

9. Medical Treatment for AIDS Is AIDS Prevention: African Americans and Latinos Are Disadvantaged

The new AIDS medicines and related services have extended life for many thousands of people with HIV/AIDS. Unfortunately, African American and Latino AIDS patients are not benefiting as much as whites from the new medicines and services. Repeatedly, studies have found racial/ethnic differences in receipt of treatment that cannot be explained by other key characteristics of the patients.[1]

Lack of appropriate care is a personal tragedy for anyone with HIV/AIDS, but its consequences extend beyond that person out into the surrounding community. Patients receiving care are less infectious because their viral load is lower.[2] Patients receiving care also have opportunities to learn on how to reduce the chances of transmitting their infection to others.[3]

Since injecting partners and sexual partners are often drawn from an individual's own racial/ethnic group, the suboptimal care received by African American and Latino AIDS patients is translating into more new infections among blacks and Latinos than might be the case if the black and Latino AIDS patients were receiving optimal care.

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Latino migration, AIDS care, and new infections

Poor Latino immigrants who have come to the United States without proper documentation are not eligible for financial assistance with their medical care.[4] This means they are less likely to be tested for HIV and if tested, to get appropriate medical treatment. The U.S. Immigration and Naturalization Service might eventually find these ill individuals and deport them. In the meantime, they are here. If they have HIV, they may well have contracted the disease here; in any case, they are human beings who need medical help. They need help both for their own sake, and for the sake of their wives, husbands, and lovers who are their uninfected sexual partners and injecting partners.

10. What Must Be Done

As a society, we claim to be concerned about the health and welfare of our citizens who use illegal drugs. Yet we provide methadone maintenance, the most effective treatment for heroin addiction, to less than one heroin user in three. At the same time, we provide almost unlimited funds to imprison users.

The Centers for Disease Control and Prevention tells us that the most effective way to prevent the spread of AIDS among injecting drug users is to make sure that each injection is made with a new, sterile needle; yet, in many cities and states, we use the government's police power to prevent injecting drug users from getting access to sterile needles.

We believe in equality before the law, but in at least some cities and states, we permit the police to practice racial profiling, causing HIV to spread much more rapidly among African Americans and Latinos than among whites who inject drugs – when, in reality, we do not want anyone to get HIV.

The federal government spends billions of dollars for HIV prevention each year. Yet not one federal prevention dollar is being spent for needle exchange programs, the most effective prevention technique for injection drug users, the group that now accounts for 35 percent of all new HIV infections.

We are concerned about rising medical costs, yet ignore the fact that it costs much less to prevent the spread of HIV through needle exchange programs and over-the-counter sales of syringes than it does to medically treat those with HIV/AIDS.

We spend hundreds of millions of dollars to treat people with HIV. No one would defend having racial preferences in how we spend those dollars. Yet our best information is that, because of inadequate medical treatment, African Americans and Latinos who inject drugs are dying from AIDS in proportionately higher numbers than whites who inject drugs.

Every year, more people who inject drugs are infected with HIV. Every year, more AIDS deaths occur. We must meet this challenge:

- We must make drug treatment available to all who need it, regardless of race/ethnicity.
- We must make AIDS treatment available to all who need it, regardless of race/ethnicity.
- We must make federal HIV prevention dollars available for needle exchange programs and other programs that increase access to sterile syringes.
- We must make hepatitis C prevention, treatment, and research a federal funding priority.
- We must follow the lead of states like Connecticut and Hawaii. We must reform our state laws and regulations to:
  - Permit and fund needle exchange programs
  - Permit pharmacies to sell syringes without prescriptions
  - Permit possession of sterile needles and related injection equipment
  - Recognize that HIV and hepatitis C prevention is a legitimate medical purpose and encourage physicians to write syringe prescriptions for people who inject drugs.

As a humane society, we can do no less.

11. Endnotes

1. Health Emergency: The Spread of AIDS Among African Americans Who Inject Drugs

[1] The number of drug-related AIDS cases includes three exposure groups: "people who inject drugs," "men who have sex with men and inject drugs," and "heterosexual partners of injecting drug users." The category "Injecting drug users" includes people who currently are injecting drugs as well as those who have injected drugs at some time in the past but who no longer do so. The data are adjusted to reduce cases with unknown exposure. Centers for Disease Control and Prevention. 2001. *HIV/AIDS Surveillance Report*. vol. 13. no. 2. tables 22-23.

[2] The Centers for Disease Control and Prevention estimates that a third of people infected with HIV are unaware of their infection status. This estimate applies to all exposure groups. Robert S. Janssen, David R. Holtgrave, Ronald O. Valdiserri and others. 2001. "The serostatus approach to fighting the HIV epidemic: prevention strategies for infected individuals." *American Journal of Public Health*. July. vol. 91. no. 7. pages 1019-1024.

[3] Dawn Day and Reuben Cohen. 1996. "Race and the spread of HIV/AIDS related to injection drug use." April 5. Princeton, NJ: Dogwood Center. 11 pages.

To look at it another way, in 2001, African Americans accounted for 55 percent of new injection-related AIDS cases although they represented only about 12 percent of the U.S. population. Centers for Disease Control and Prevention. 2001. *HIV/AIDS Surveillance Report*. vol. 13. no. 2. tables 22-23.

[4] Injection-related here includes two exposure groups: "IV drug use (female and heterosexual male)" and "men who have sex with men and inject drugs." Data are from the Centers for Disease Control and Prevention AIDS Public Data Set. Available at http://wonder.cdc.gov/wonder/

[5] As a cause of death among African Americans (non-Hispanic) in 2000, AIDS was:

- third for those aged 25-34
- third for those aged 35-44
- third for those aged 45-54

See National Vital Statistics Reports. 2002. *Deaths: Leading Causes for 2000*. Hyattsville, MD: National Center for Health Statistics. by Robert N. Anderson. vol. 50. no. 16. September 16. table 2.

[6] The assumption is that, for African Americans, the proportion of cumulative, drug-related AIDS cases and the proportion of drug-related AIDS deaths are roughly the same. Centers for Disease Control and Prevention. *2001. HIV/AIDS Surveillance Report*. vol. 13. no. 2. tables 22-23.

[7] Kaiser Family Foundation. 2001. "African Americans' views of the HIV/AIDS epidemic at 20 years: findings from a national survey." Menlo Park, CA. page 15.

[8] David R. Holtgrave, Steven D. Pinkerton, T. Stephen Jones, and others. 1998. "Cost and cost-effectiveness of increasing access to sterile syringes and needles as an HIV prevention intervention in the United States," *Journal of Acquired Immune Deficiency Syndromes*. vol. 18 (supplement). pages S133-S138.

[9] David Cole. 1999. *No Equal Justice*. New York: The New Press. 218 pages. Human Rights Watch. 2000. "Punishment and prejudice: racial disparities in the war on drugs." May. Go to http://www.hrw.org/reports/2000/usa/

[10] The drug use data are for any illicit drug used in the past year in 1998 and are from U.S. Department of Health and Human Services. Substance Abuse and Mental Health Services Administration. 1999. *National Household Survey On Drug Abuse: Population Estimates 1998*. tables 2B, 2C and 2D. In this data set, black excludes Hispanic blacks. The arrest data are arrests for possession or sale of any illicit drug in 2000 and are unpublished data from the Federal Bureau of Investigation. In this data set, "black" includes Hispanic blacks.

[11] Bureau of Justice Statistics. 2001. "Fact sheet: traffic stop data collection policies for state police, 2001." December. 4 pages. William K. Rashbaum. 2000. "Review board staff faults police on stop-and-frisk reports," *New York Times*, April 28. page B1.

[12] In an examination of possible explanations for the high black/white ratio of AIDS deaths among injecting drug users, Dr. Day found that racial profiling contributed more to the black/white differential than did racial differences in injecting drug use, genetic differences or racial differences in medical care. Dawn Day. 2000. "The role of racial profiling in spreading AIDS among African Americans who inject drugs." *Fordham Urban Law Journal*. October. pages 70-77.

[13] J.H. Jones. 1993. Bad blood: the Tuskegee syphilis experiment. New York: Free Press. 2nd edition.

[14] F. Libert, P. Cochaux, G. Beckman, and others. 1998. "The deltaccr5 mutation conferring protection against HIV-1 in Caucasion populations has a single and recent origin in northeastern europe." *Human Molecular Genetics*. March. vol. 5. no. 3. pages 399-406; J.J. Martinson, N.H. Chapman, D. C. Rees, and others. 1997. "Global distribution of CCR5 gene 32-basepair deletion." *Nature Genetics*. May. vol.16. no.1. pages 100-103; Y. Lu, V. R. Nerurkar, W. M. Dashwood, and others. 1999. "Genotype and allele frequency of a 32-base pair deletion mutation in the CCR5 gene in various ethnic groups: absence of mutation among Asians and Pacific Islanders." *International Journal of Infectious Diseases*. Summer. vol. 3. no. 4. pages 186-191.

2. Health Emergency: The Spread of AIDS Among Latinos Who Inject Drugs

[1] See footnote 1 of Chapter 1.

[2] See footnote 2 of Chapter 1.

[3] The estimate of 1.5 to 1 is derived from a study of injecting drug users in drug treatment, done in 1991-92. Centers for Disease Control and Prevention. *National HIV Serosurveillance Summary, Results Through 1992*. vol. 3. page 19. Based on a comparison in heroin use and needle use in the past year (3-year average for 1996 - 1998) and AIDS cases among injecting drug users by race/ethnicity for 1998, the difference between the two groups would be even greater, with Latinos who inject drugs about four times as likely as whites to get AIDS. The drug use data are from the National Household Survey of Drug Abuse. The AIDS data are unpublished data from the Centers for Disease Control and Prevention.

To look at it another way, Latinos accounted for 22 percent of new injection-related AIDS cases in 2001 although they represented only about 11 percent of the population. Centers for Disease Control and Prevention. 2001. *HIV/AIDS Surveillance Report*. vol. 13. no. 2. tables 22-23.

[4] See footnote 4 of Chapter 1.

[5] As a cause of death among Latinos in the U.S. in 2000, AIDS was:

- fifth for those aged 25-34
- third for those aged 35-44
- fifth for those aged 45-54

National Vital Statistics Reports. 2002. *Deaths: Leading Causes for 2000*. Hyattsville, MD: National Center for Health Statistics. by Robert N. Anderson. vol. 50. no. 16. September 16. table 2. Latino AIDS deaths probably are understated in U.S. statistics because some immigrants, after becoming HIV infected in the United States, return home to be cared for by relatives before they die.

[6] The assumption is that, for Latinos, the proportion of cumulative, drug-related AIDS cases and the proportion of drug-related AIDS deaths are roughly the same. Centers for Disease Control and Prevention. 2001. *HIV/AIDS Surveillance Report*. vol. 13. no. 2; tables 22-23.

[7] Kaiser Family Foundation. 2001. "Latinos' views of the HIV/AIDS epidemic at 20 years: findings from a national survey." Menlo Park, CA. page 19.

[8] For a fuller explanation of the negative impact of racial/ethnic profiling, see the previous chapter. See also National Council of La Raza. 2002. "Testimony on drug sentencing and its effects on the Latino community." Testimony before the United States Sentencing Commission by Charles Kamasaki, Senior Vice President. February 25; National Council of La Raza. 1999. "NCLR, Hispanic law enforcement organizations, form partnership to address harassment and abuse of Latinos." December 15. The Hispanic law enforcement organizations are the Hispanic American Police Command Officers Association and the National Latino Peace Officers Association, the two largest associations representing Hispanic law enforcement personnel in the country.

[9] Diane Smith. 2001. "Barriers hinder treatment of HIV among immigrants who live here illegally." *Fort Worth Star-Telegram*." May 25. In 2002, 7 out of every 10 patients diagnosed with AIDS at La Clinica del Pueblo in Washington, D.C. arrived at near-death stages of the AIDS. Steven Gray. 2002. "AIDS services slow in reaching Latinos; number of new infections rising." *Washington Post*. April 22. An untreated HIV-infected person has a higher viral load and thus is more infectiousness during sexual and drug-using exposures than would be the case if that person had access to appropriate medical care. Robert S. Janssen, David R. Holtgrave, Ronald O. Valdiserri, and others. 2001. "The serostatus approach to fighting the HIV epidemic: prevention strategies for infected individuals." *American Journal of Public Health*. July. vol. 91 no. 7. page 1021.

[10] Diane Smith. 2001. "Barriers hinder treatment of HIV among immigrants who live here illegally." *Fort Worth Star-Telegram*." May 25.

[11] F. Libert, P. Cochaux, G. Beckman, and others. 1998. "the deltaccr5 mutation conferring protection against HIV-1 in Caucasion populations has a single and recent origin in northeastern europe." *Human Molecular Genetics*. March. vol. 5. no. 3. pages 399-406; J.J. Martinson, N.H. Chapman, D.C. Rees, and others. 1997. "Global distribution of CCR5 gene 32-basepair deletion." *Nature Genetics*. May. vol.16. no.1. pages 100-103;

Y. Lu, V. R. Nerurkar, W. M. Dashwood, and others. 1999. *International Journal of Infectious Diseases.* "Genotype and allele frequency of a 32-base pair deletion mutation in the CCR5 gene in various ethnic groups: absence of mutation among Asians and Pacific Islanders." summer. vol. 3. no. 4. pages 186-191.

3. A Neglected Opportunity: Drug Treatment as AIDS Prevention

[1] National Research Council. 2001. *Informing America's Policy On Illegal Drugs: What We Don't Know Keeps Hurting Us.* Washington, D.C.: National Academy Press. page 242. Limited resources create opportunities for discrimination. See L. M. Lundgren, M. Amodeo, F. Ferguson, and K. Davis. 2001. "Racial and ethnic differences in drug treatment entry of injection drug users in Massachusetts." *Journal of Substance Abuse Treatment.* October. vol. 21. no 3. pages 145-153.

[2] John Donnelly. 2001. "U.S. is said to overstate spending on drug care." *Boston Globe.* January 24. page 1. See also Patrick Murphy, Lynn E. Davis, Timothy Liston, and others. 2000. *Improving Anti-Drug Budgeting.* Menlo Park, CA: The Rand Corporation. http://www.rand.org/publications/MR/MR1262/

[3] Christopher S. Wren. 1999. "Top U.S. drug official proposes shift in criminal justice policy." *New York Times.* December 9. page A23; and George D. Lundberg. 1999. "New winds blowing for American drug policies." *Journal of the American Medical Association.* September 17. pages 946-947.

[4] Every $1 invested in treatment reduces the costs of drug-related crime, criminal justice costs, and theft by $4 to $7. When health care savings are added in, the total savings from drug treatment exceeds the cost of drug treatment by a ratio of 12 to 1. Centers for Disease Control and Prevention. 2002. "Substance abuse treatment for injection drug users: a strategy with many benefits." February. page 2. http://www.cdc.gov/idu/substance.htm

[5] National Research Council. 2001. *Informing America's Policy On Illegal Drugs: What We Don't Know KHeeps Hurting Us.* Washington, D.C.: National Academy Press. page 243.

4. The Scientific Evidence: Needle Access Programs Prevent HIV and Reduce Drug Use

[1] Centers for Disease Control and Prevention; Public Health Service; National Institute on Drug Abuse; and Substance Abuse and Mental Health Services Administration. 1997. "HIV prevention bulletin: medical advice for persons who inject illicit drugs." May 9. Go to http://www.cdc.gov/idu/pubs/hiv_prev.htm

[2] D.R. Gibson, N.M. Flynn, and D. Perales. 2001. "Effectiveness of syringe exchange programs in reducing HIV risk behavior and HIV seroconversion among injecting drug users." *AIDS.* July 27. vol. 15. no. 11. pages 1329-1341. David Vlahov, D.C. Des Jarlais, Eric Goosby, and others. 2001. "Needle exchange programs for the prevention of human immunodeficiency virus infection: epidemiology and policy." *American Journal of Epidemiology.* vol. 154 (supplement). no. 12. pages S70-S77.

[3] Samuel R. Friedman, Theresa Perils, and Don C. Des Jarlais. 2002. "Laws prohibiting over-the-counter syringe sales to injection drug users: relations to population density, HIV prevalence and HIV incidence. *American Journal of Public Health.* vol. 91. pages 791-793.

[4] The reports are by the National Commission on AIDS; General Accounting Office; University of California; National Research Council and Institute of Medicine (2 reports); Office of Technology Assessment of the U.S. Congress; National Institutes of Health Consensus statement; and a report by the then Surgeon General, David Satcher. Go to http://www.dogwoodcenter.org/science/20science.html

[5] For links to their statements, go to http://www.dogwoodcenter.org/science/10science.html These statements and the research reports cited in the footnote above all were part of the as-yet-unsuccessful effort to achieve federal funding for needle exchange programs. See also David Vlahov, D.C. Des Jarlais, Eric Goosby, and others. 2001. "Needle exchange programs for the prevention of human immunodeficiency virus infection: epidemiology and policy." *American Journal of Epidemiology*. vol. 154. (supplement) no. 12. pages S70-S77.

[6] The federal government spent almost $1 billion dollars ($968 million) on HIV prevention in FY2002. Priya Alagiri, Todd Summers, and Jennifer Kates. 2002. "Spending on the HIV/AIDS epidemic: trends in U. S. Spending of HIV/AIDS." July. Menlo Park. CA: Kaiser Family Foundation. 8 pages. http://www.kff.org/content/2002/20020706a/

[7] Drug-related AIDS accounted for 35 percent of all new AIDS infections in 2001. This includes three exposure groups: injecting drug users. men who have sex with men and inject drugs; and heterosexual partners of injecting drug users. Centers for Disease Control and Prevention. 2001. *HIV/AIDS Surveillance Report*. vol. 13. no. 2. tables 22-23.

David Vlahov, D.C. Des Jarlais, Eric Goosby, and others. 2001. "Needle exchange programs for the prevention of human immunodeficiency virus infection: epidemiology and policy." *American Journal of Epidemiology*. vol. 154 (supplement). no. 12. pages S70-S77.

[8] National Institute on Drug Abuse. 2002. "Principles of HIV prevention in drug-using populations: a research-based guide." March. page 18. Available at http://www.drugabuse.gov/POHP/index.html

[9] Edward H. Kaplan and Elaine O'Keefe. 1993. "Let the needles do the talking! evaluating the New Haven needle exchange." *Interfaces*. January-February. vol. 23. no. 1. pages 7-26. Robert Heimer, Kaveh Khoshnood, P. Clay Stepens, and others. 1996. "Evaluating a needle exchange programme: models for testing HIV-1 risk reduction." *International Journal of Drug Policy*. vol. 7. no. 2. pages 123-129.

[10] Baltimore, MD: Since August 1994, approximately 1,400 injecting drug users have sought drug treatment through referrals from the needle exchange program. Moher Downing, Karen Vernon, Thomas H. Reiss, and others. 2002. "Final report to HIV prevention trails network: community acceptance and implementation of HIV prevention interventions for injection drug users." January. 40 pages. Available at http://www.drugpolicy.org See also R. Brooner, M. Kidorf, V. King, and others. 1998. "A drug abuse treatment success among needle exchange participants." *Public Health Reports*. June. vol. 113 (supplement 1). pages 130-139.

Hawaii: Don C. Des Jarlais, Mark Breda, and Suzette Smetka. 1998. "Hawaii syringe exchange program: 1997 evaluation report." Available from the Chow Project. 710 North King Street. Room #5. Honolulu. Hawaii 96817; 37 pages plus figures.

Seattle, WA: H. Hagen, J.P. McGough, H. Thiede, and others. 2000. "Reduced injection frequency and increased entry and retention in drug treatment associated with needle exchange participation in Seattle drug injections. *Journal of Substance Abuse Treatment*. vol. 19. pages 247-252.

Tacoma, WA: H. Hagan. D.C. Des Jarlais, D. Purchase, and others. 1993. "An interview study of participants in the Tacoma syringe exchange." *Addiction*. vol. 88 pages 1691-1697.

[11] Ricky N. Bluthenthal. 1997. "Impact of law enforcement on syringe exchange programs: a look at Oakland

and San Francisco." *Medical Anthropology*. vol. 18. pages 61-83.

5. The Legality of Saving Lives

[1] See footnote 1 of Chapter 4.

[2] Lawrence O. Gostin, Zita Lazzarine, T. Stephen Jones, and Kathleen Flaherty. 1997. "Prevention of HIV/AIDS and other blood-borne diseases among injection drug users: a national survey on the regulation of syringes and needles." *Journal of the American Medical Association*. January 1. vol. 277. pages 53-62.

[3] The overview of the process of needle access reform is based on Dr. Dawn Day's numerous conversations with leaders in the needle exchange movement. The information on the legal situation in particular states with regard to prescription laws or paraphernalia laws is taken from Scott Burris, Peter Lurie, Daniel Abrahamson, and Josiah D. Rich. 2000. "Physician prescribing of sterile injection equipment to prevent HIV infection: time for action." *Annals of Internal Medicine*. August. vol. 133. pages 218-226. Josiah D. Rich and others. "The genesis of syringe prescription to prevent HIV in Rhode Island." Go to www.temple.edu/lawschool/aidspolicy/ and click on "one physician's experience."

[4] For a list of states where needle exchange is legal or permissible, see Heather Sidwell and Amanda Watson as updated by Julie Scales. 2001. "Needle exchange and access to sterile syringes." April 30. Go to http://www.stateserv.hpts.org/# On the website first go to "HIV/AIDS & STDs." and then "Issue Briefs."

[5] Celeste Katz. 2002. "Needle access difficult in Bronx." *New York Daily News*. July 20. A study of over-the-counter sales of syringes in New York City found that syringe monitors were able to successfully buy syringes without inappropriate questions and with a safety insert and disposal information upon request in 7 percent of the pharmacy visits.

[6] W. M. Compton, L. B. Cottler, S. H. Decker, and others, 1992. "Legal needle buying in St. Louis." *American Journal of Public Health*. vol. 82. no. 4. pages 595-596. See also Centers for Disease Control and Prevention. 2002. "Pharmacy sales of sterile syringes." January. Go to http://www.cdc.gov/idu

[7] Josiah D. Rich and others. "The genesis of syringe prescription to prevent HIV in Rhode Island" Go to www.temple.edu/lawschool/aidspolicy/ and click on "one physician's experience."

[8] This information is as of June 1, 2002 and is from the website of Scott Burris, Project on Harm Reduction in the Health Care System at the Temple University Beasley School of Law. Go to http://www.temple.edu/lawschool/aidspolicy/ and click on "50 states at a glance." See also Centers for Disease Control and Prevention. 2002. "Physician prescription of sterile syringes to injection drug users." February. Go to http://www.cdc.gov/idu

[9] This is the information as of June 1, 2002 and is from the website of Scott Burris, *Project on Harm Reduction in the Health Care System* at the Temple University Beasley School of Law. Go to http://www.temple.edu/lawschool/aidspolicy/ and click on "syringe deregulation."

[10] Don C. Des Jarlais, Courtney McKnight, Karen Eigo and Patricia Friedmann. 2002. "National syringe exchange syringe 2000" Slide presentation at the North American Syringe Exchange Convention. April. Albuquerque, NM.

[11] Centers for Disease Control and Prevention. 2002. "Syringe exchange programs." and "Syringe disposal." January. Go to http://www.cdc.gov/idu

[12] Courtney McKnight, Don C. Des Jarlais, Karen Eigo and others. 2002. "Smaller SEPs: a description from the 2000 national syringe exchange survey." April. Slide presentation at the North American Syringe Exchange convention. Albuquerque, NM.

[13] The illegal exchanges are often able to exist in a relatively public fashion because, while needle access laws and regulations have not yet been reformed in some areas, many officials nonetheless understand that it makes no sense to arrest people working to stem an epidemic. Courtney McKnight, Don C. Des Jarlais, Karen Eigo, and others. 2002. "Smaller SEPs: a description from the 2000 national syringe exchange survey." April. Slide presentation at the North American Syringe Exchange convention. Albuquerque, NM. See also Scott Burris, Davis Finucane, Heather Gallagher, and Joseph Grace, 1996. "The legal strategies used in operating syringe exchange programs in the United States." *American Journal of Public Health*. August. vol. 86. pages 1161-1166.

[14] Laura Mansnerus. 2001. "Addict's suit claims policy ignore needle-swap law." *New York Times*. January 1. page B1.

[15] Ricky N. Bluthenthal, Alex H. Kral, Jennifer Lorvick, and John K. Watters, 1997. "Impact of law enforcement on syringe exchange programs: a look at Oakland and San Francisco." *Medical Anthropology*. vol. 18. pages 61-83.

[16] See chapter 4 of this report for a discussion of the effectiveness of needle exchange programs in getting users into drug treatment.

[17] This is what happened in New Jersey. See Dawn Day. 1998. "Sad termination of a life-saving project." *Trenton Times*. December 25. page A13.

[18] Valleroy, L.A., B. Weinstein, T.S. Jones, and others. 1995. "Impact of increased legal access to needles and syringes on the practices of injecting drug users and police officers – Connecticut, 1992-93. *Journal of Acquired Immune Deficiency Syndromes*. vol. 10. page 829.

[19] Dawn Day. 1999. "States and metro areas hardest hit by the HIV/AIDS epidemic." Princeton, N.J.: Dogwood Center. November. Go to http://www.dogwoodcenter.org/top/topview.html

[20] The estimate of 14,000 new drug-related HIV cases each year is calculated by multiplying 40,000 by 35 percent. The Centers for Disease Control and Prevention estimate of 40,000 new cases a year for all exposure groups is taken from Robert S. Janssen, David R. Holtgrave, Ronald O. Valdiserri and others, 2001. "The serostatus approach to fighting the HIV epidemic: prevention strategies for infected individuals." *American Journal of Public Health*. July. vol. 91. no. 7. pages 1019-1024. The estimate that 35 percent of all new HIV infections are injection-related is based on the percent of new AIDS cases in 2001 involving 3 exposure groups: "injecting drug use," "men who have sex with men and inject drugs" and "heterosexual partners of injecting drug users." Centers for Disease Control and Prevention. 2001. *HIV/AIDS Surveillance Report*. vol. 13. no. 2. tables 22-23.

6. Saving Lives and Saving Billions of Health Care Dollars

[1] See footnote 10 of Chapter 5.

[2] Robert S. Janssen, David R. Holtgrave, Ronald O. Valdiserri, and others. 2001. "The serostatus approach to fighting the HIV epidemic: prevention strategies for infected individuals." *American Journal of Public Health*. July. vol. 91. no. 7. pages 1019-1024. Centers for Disease Control and Prevention. 2002. "Syringe exchange programs." January, 4 pages. According to the Centers for Disease Control and Prevention, "The cost per HIV infection prevention by syringe exchange programs has been calculated at $4,000 to $12,000, considerably less than the estimated $190,000 medical costs of treating a person infected with HIV." Go to http://www.cdc.gov/idu See also David R. Holtgrave, Steven D. Pinkerton, T. Stephen Jones and others. 1998. "Cost and cost-effectiveness of increasing access to sterile syringes and needles as an HIV prevention intervention in the United States." *Journal of Acquired Immune Deficiency Syndromes*. vol. 18 (supplement). pages S133-S138.

[3] The estimate of 80,000 over five years is based on multiplying 16,000 new drug-related HIV/AIDS cases per year by 5. For details of the 16,000 estimate, see the section, "The Continuing Epidemic" in Chapter 5.

[4] In 1989, Congress declared that no federal money could be spent to support clean-needle programs until the federal government could provide scientific evidence that such programs both reduced the spread of HIV and did not encourage drug use. In April 1998, after a meticulous review of the scientific evidence, Health and Human Services Secretary Donna Shalala certified that the congressional mandate had been met.

Although Secretary Shalala did certify that needle exchange programs are effective, she did not release federal HIV prevention funds for this purpose. This policy continues under President Bush. David Vlahov, D.C. Des Jarlais, Eric Goosby, and others. 2001. "Needle exchange programs for the prevention of human immunodeficiency virus infection: epidemiology and policy." *American Journal of Epidemiology*. vol. 154 (supplement). no. 12. pages S70-S77.

[5] For the scientific evidence as put forth by our public health experts, see Chapter 4. See also Paul Bedard. 1998. "Black caucus targets drug czar." *Washington Times*. April 25. page 1; Representative Xavier Becerra and Representative Maxine Waters. 1998. Letter to Secretary of Health and Human Services Donna Shalala. February 9; Donna Christian-Christensen, MD. 2002. Interview by George Strait on the Kaiser Family Foundation website. July 10; Kweisi Mfume (chief executive of the NAACP). 1998. "Letter to the editor." *New York Times*. July 11. page A10.

[6] The failure is at the highest levels of the government. The public health establishment within as well as outside the federal government has come out solidly in favor of needle exchange programs. See Chapter 4.

7. Health Emergency: African American and Latina Women and Their Children

[1] The number of drug-related AIDS cases among women includes two exposure groups: "women who inject drugs," and "women who are the heterosexual partners of injecting drug users." Injecting drug users includes people who are currently injecting drugs as well as people who have injected drugs at some time in the past but who no longer do so. The data are adjusted to reduce cases with unknown exposure. Centers for Disease Control and Prevention. 2001. *HIV/AIDS Surveillance Report*. vol. 13. no. 2. table 23.

[2] As a cause of death among African American women (non-Hispanic) in 2000, AIDS was:

- first for those aged 25-34
- third for those aged 35-44
- fifth for those aged 45-54

As a cause of death among Latinas in 2000, AIDS was:

- fourth for those aged 25-34
- fourth for those aged 35-44
- seventh for those aged 45-54

National Vital Statistics Reports. 2002. *Deaths: Leading Causes for 2000.* Hyattsville, MD: National Center for Health Statistics. by Robert N. Anderson. vol. 50. no. 16. September 16. table 2.

[3] Centers for Disease Control and Prevention. 2001. *HIV/AIDS Surveillance Report.* vol. 13. no. 2. Table 23.

[4] Centers for Disease Control and Prevention. 2001. *HIV Prevention Strategic Plan Through 2005.* January. page 7.

[5] In the absence of any medical treatment, about 75 out of 100 infants of HIV-infected mothers are born free of HIV. Given appropriate medical treatment during pregnancy and birth, an infant's chance of being born free of HIV disease now rises to as high as 98 in 100. Howard Minkoff and Nanette Santoro. 2000. "Ethical considerations in the treatment of infertility in women with human immunodeficiency virus infection." *New England Journal of Medicine.* June 8. vol. 342. no. 23. pages 1748-1750.

[6] Jerome Socolovsky. 2002. "Study: HIV among U.S. newborns drops." Associated Press. July 9. See also Howard Minkoff and Nanette Santoro. 2000. "Ethical considerations in the treatment of infertility in women with human immunodeficiency virus infection." *New England Journal of Medicine.* June 8. vol. 243. no. 23. pages 1748-1750.

[7] Some 80 percent of all children age 12 and younger with HIV/AIDS through 2001 were black or Latino. Centers for Disease Control and Prevention. 2001. *HIV/AIDS Surveillance Report.* vol. 13. no. 2. tables 15-16.

[8] The estimate takes into account the deaths to AIDS-infected children; thus the estimate refers only to children alive in 1998. Personal communication from David Michaels based on his 1992 article, "Estimates of the number of motherless youth orphaned by AIDS in the United States." *Journal of the American Medical Association.* December 23/30. vol. 268. no. 24; UNAIDS reported an estimate of 70,000 orphans for the United States for 1997. UNAIDS. 1998. *Report on the Global HIV/AIDS Epidemic.* New York, NY: UNAIDS. June. page 66.

[9] Based on cumulative AIDS cases among women through 2001. Centers for Disease Control and Prevention. 2001. *HIV/AIDS Surveillance Report.* vol. 13. no. 2. table 23.

[10] Don C. Des Jarlais and Salaam Semaan. 2002. "HIV prevention research: cumulative knowledge or accumulating studies: an introduction to the HIV/AIDS prevention research synthesis project supplement." *Journal of Acquired Immune Deficiency Syndromes.* July 1. vol. 30 (supplement 1). pages S1 - S7.

8. Hepatitis C: A Sometimes Deadly Disease Where Sterile Needles Can Save Lives and Dollars

[1] National Institute on Drug Abuse. 2000. "Community drug alert bulletin: hepatitis C." May. 4 pages.

[2] *Morbidity and Mortality Weekly Report*. 2001. "Public health and injection drug use." May 18. vol. 50. no. 19. page 377.

[3] National Institutes of Health Consensus Development Conference. 2002. "Preliminary draft statement: Management of hepatitis C." June 12. 38 pages. http://consensus.nih.gov/cons/116/116cdc_intro.htm

[4] Preliminary analyses indicate that viral clearance is less common in blacks than in whites. David L. Thomas, Jacquie Astemborski, Rudra M. Rai and others. 2000. "The natural history of hepatitis C virus infection." *Journal of the American Medical Association*. July 26. vol. 284. no.4. pages 450-456.

[5] Jerome Groopman. 1998. "The shadow epidemic." *New Yorker*. May 11. pages 48-60.

[6] Long-term monogamous sexual partners of persons infected with hepatitis C have a very low risk of infection. Prior to 1992, when an effective test for the presence of hepatitis C in donated blood was developed, people who had blood transfusions were at risk for hepatitis C. That risk is now extremely low. National Institute on Drug Abuse. 2000. "Community drug alert bulletin: hepatitis C." May. 4 pages.

9. Medical Treatment for AIDS is AIDS Prevention: African Americans and Latinos are Disadvantaged

[1] Kevin C. Heslin and William E. Cunningham. 2001. "African Americans and AIDS: Issues in access to care." *Minority Health Today, Mobilizing to fight HIV/AIDS in the African-American community*. Jennifer C. Friday, Marsha Lillie-Blanton and Jennifer Kates, eds. (April supplement). pages 22-32; M.F. Shapiro, S.C. Morton, D.F. McCaffrey, and others. 1999. "Variations in the care of HIV-infected adults in the United States: results from the HIV cost and services utilization study". *Journal of the American Medical Association*. June 23-30. vol. 281. no. 24. pages 2305-2314; Jolyn Pratt Montgomery, Brenda W. Gillespie, Ann C. Gentry, and others. 2002. "Does access to health care impact survival time after diagnosis of AIDS?" *AIDS Patient Care and STDs*. May. vol. 16. no. 5. pages 223-231; Seth C. Kalichman, Jeffrey Graham, Luke Webster and James Austin. 2002. "Perceptions of health care among persons living with HIV/AIDS who are not receiving antiretroviral medications." *AIDS Patient Care and STDs*. May. vol. 16. no. 5. pages 233-240.

[2] Thomas C. Quinn, Maria J. Wawer, Nelson Sewankambo, and others. 2000. "Viral load and heterosexual transmission of human immunodeficiency virus type 1." *New England Journal of Medicine*. March 30. vol. 342. no. 13. pages 921-929.

[3] Philip S. Rosenberg. 2001. "HIV in the late 1990s: what we don't know may hurt us." *American Journal of Public Health*. July. vol. 91. no. 7. pages 1016-1017.

[4] Somini Sengupta. 1997. "Law curtails help for illegal immigrants with AIDS." *New York Times*. December 29. page B1.

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